

### **Overview**

# **Points To Remember About Fibrous Dysplasia**

- Fibrous dysplasia happens when healthy bone is replaced with other types of tissue.
- Bones may become oddly shaped or even break. You may also feel pain.
- Fibrous dysplasia is caused by a problem with a gene in the cells that form bone and other tissues.
- Medications, surgery, and a cast may be used to treat symptoms of the disease.
- Talk to your doctor about an exercise and diet program that will keep your bones healthy.

Fibrous dysplasia occurs when areas of healthy bone are replaced with fibrous, or connective, tissue. This can lead to pain and misshapen or fractured bones, especially when the disease occurs in the arms and legs. If it occurs in the skull it can cause the shape of the head or face to change. In rare cases, hearing and vision loss can also occur.

Some people with fibrous dysplasia have only one bone involved, whereas other people have more than one bone involved. The disease may occur alone, or as part of a condition known as McCune-Albright syndrome.

## What happens in fibrous dysplasia?

In fibrous dysplasia, bone-forming cells fail to mature. Instead, they produce too much connective tissue.

The disease can affect any bone in the body. The most common sites are the bones in the skull and face, thighbone, shinbone, upper arm, pelvis, and ribs. Affected bones are often found on one side of the body, although the disease does not spread from one bone to another.

### Who Gets

Fibrous dysplasia is caused by a defective gene in the cells that form bone and other affected tissues. This gene is not inherited from your parents, and you will not pass the disease to your children.

Fibrous dysplasia is not common. It is usually diagnosed in children and young adults, and is present throughout life. The likelihood of getting the disease does not appear to be influenced by gender, race, ethnic background, geographic location, or environment.

# **Symptoms**

The most common symptoms of fibrous dysplasia include:

- Pain.
- Misshapen bones.
- Broken bones, which are more common between the ages of six and 10.

Other symptoms depend on the bones that are affected and can include:

- Legs of different lengths, leading to a limp.
- Long-term sinus congestion.
- In very rare cases, vision loss or cancer.

# **Diagnosis**

To diagnose you with fibrous dysplasia, your doctor may use one or more of the following tests:

- X-rays of your bones.
- Magnetic resonance imaging (MRI) or computed tomography (CT).
- Small bone sample.

It's not clear whether testing for the problem gene is useful.

## **Treatment**

There is no cure for fibrous dysplasia. Doctors will treat the symptoms with treatments such as:

Cast for broken bones.

- Surgery to:
  - Repair broken bones.
  - Prevent fracture.
  - Correct the shape of a bone.
  - o Relieve bone pain.
- Medications, such as bisphosphonates, that can reduce pain associated with the disease.

# **Living With**

Besides seeing your doctor, there are a few things you can do to keep your bones healthy:

- Exercise: talk to your doctor before beginning an exercise program.
- Diet: you should eat foods that are high in calcium, phosphorus, and vitamin D.

# **Research Progress**

Scientists are studying fibrous dysplasia to better understand how to manage the disease and its symptoms. Research activities include:

- A tool that measures how fibrous dysplasia impacts quality of life.
- Evaluation of medications used to treat the disease.
- Continued insights into the genetics and biology of the disease, to help build better treatments.

## **Related Resources**

#### **U.S. Food and Drug Administration**

Toll free: 888-INFO-FDA (888-463-6332)

Website: https://www.fda.gov

Drugs@FDA at <a href="https://www.accessdata.fda.gov/scripts/cder/daf">https://www.accessdata.fda.gov/scripts/cder/daf</a>. Drugs@FDA is a searchable catalog of FDA-approved drug products.

### Centers for Disease Control and Prevention, National Center for Health Statistics

Website: https://www.cdc.gov/nchs

#### National Institute of Dental and Craniofacial Research

Website: https://www.nidcr.nih.gov

#### **Genetic and Rare Diseases Information Center**

Website: https://rarediseases.info.nih.gov/diseases/6444/fibrous-dysplasia

#### **American Academy of Orthopaedic Surgeons**

Website: https://www.aaos.org

**Fibrous Dysplasia Foundation** 

Website: https://www.fibrousdysplasia.org

The MAGIC Foundation

Website: https://www.magicfoundation.org

Rare Bone Disease Alliance Website: http://rbdalliance.org/

If you need more information about available resources in your language or other languages, please visit our webpages below or contact the NIAMS Information Clearinghouse at NIAMSInfo@mail.nih.gov.

- Asian Language Health Information
- Spanish Language Health Information

#### Join a Clinical Trial

Find a Clinical Trial

**Related Information** 

Healthy Bones Matter: Kids' Fact Sheet

View/Download/Order Publications

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